PEMRIG

PARKINSON'S EAST MIDLANDS RESEARCH INTEREST GROUP

Newsletter – February 2025

Hello to all East Midlands' and wider people with Parkinson's (PwPs), carers, families, health professionals and others reading this February 2025 edition of the PEMRIG newsletter. Please consult the PEMRIG website (https://pemrig.org.uk) for details of past laboratory visits and research seminars, including talks from our successful Face 2 Face meeting last September.

PEMRIG is one of thirteen Parkinson's UK affiliated 'Research Interest Groups' around the UK. The aim of the RIGs is to interest PwPs, their carers and friends in the exciting Parkinson's research going on in the UK and all round the world. By following the research, we can see that steady progress is being made to understand and conquer Parkinson's'.

If you have friends or know anyone who would like to be added to PEMRIG's mailing list for this monthly newsletter, please get them to contact Liz Nash, Research Support Network Lead at Parkinson's UK (PUK), by email at: lnash@parkinsons.org.uk

Exciting trial news for 2025

The editor reports: *A recent Cure Parkinson's Trust webinar entitled* ***'Advancing Parkinson's Trial Designs'*** *got me quite excited. It was about the forthcoming EJS ACT-PD MAMS trial which is due to start recruiting this summer across several centres in the UK and which will need over 1500 PwP volunteers*. **The trial website is here: https://ejsactpd.com/**

*I mentioned some details of this first 'MAMS' trial for Parkinson's in last December's PEMRIG newsletter because it sounds such a promising way of speeding up the testing of a drug which can slow, stop or even reverse Parkinson's progression. To recap, MAMS stands for "****Multi-Arm, Multi-Stage****" clinical trial design. I learned from the Webinar that using this MAMS approach several compounds each in a separate group or arm of volunteers will be tested simultaneously in a single study against one common placebo group.* The MAMS design sounds complicated to set up and monitor but it allows for the rapid identification of promising candidates, the removal of ineffective ones and the replacement in that arm with a new compound to be tested. For a compound that shows promise the parameters of the trial in that arm can be expanded (Multi-Stage) from a Phase 2 aspect to the essential Phase 3 giving data for approval for clinical use.

The design of the MAMS trial is described here.

I learned from the Webinar that for once there will be no upper age limit. Further, volunteers in each separate arm will be able to continue taking their normal medication during the trial, if selected to join. This is a common difficulty that has prevented some PwP taking part in a trial. I also learned that a call for volunteers should go out this summer and that **Terazosin (a prostate drug), UDCA** (used to treat liver disease) and Telmisartan (used to treat high blood pressure) all of which have shown promise in smaller earlier trials, will be tested in this first MAMS trial. Watch his space for more information!

Please click here to access the full webinar mentioned above.

URGENT APPEAL

VOLUNTEERS WITH PARKINSON'S ARE NEEDED AT NOTTINGHAM UNIVERSITY FOR RESEARCH INTO REDUCING TREMOR

About the study: Dr Kat Gialopsou of the School of Psychiatry at the University of Nottingham needs **30 PwP** to take part in an exciting research study to explore a safe, non-invasive technique to reduce tremor in Parkinson's. This new technique involves **median nerve stimulation (MNS)**, combined with **brain activity monitoring using EEG**. The team are investigating how different frequencies of gentle wrist MNS affects Parkinson's symptoms, such as tremor, and influences brain activity. This promising approach has **already shown success in managing symptoms of other neurological conditions**. Their research aims to identify the optimal stimulation frequency for tremor relief in individuals with Parkinson's.

What Does the Study Involve? Participants will take part in **3 study sessions**, each spaced at least 2 days apart. **Session 1**: Lasts approximately 3 hours (includes questionnaires and baseline measurements). **Sessions 2 and 3**: Each less than 2 hours. During each session, you will: **Receive wrist stimulation** (median nerve stimulation) at different frequencies in each session. The stimulation lasts less than 30 minutes. And you will have **your brain activity recorded** using **electroencephalography (EEG)**. This is a non-invasive technique that measures electrical activity in the brain using small sensors placed on the scalp.

Who Can Participate? Adults diagnosed with Parkinson's, can attend 3 sessions at our research facility and have not received any neurostimulation in a 6-month period before the study starts.
Anyone with a pacemaker or insulin pump cannot participate.

Where Does the Study Take Place? The sessions will be held at the School of Psychology, Park Campus, University of Nottingham, with Kat's experienced and friendly research team ensuring your comfort and safety throughout. Blue badge parking slots are available if needed and water is available if a drink is needed. There is lift access to our study room. Expenses are available for volunteers coming from outside Nottingham - see information sheet!
To register your interest and/or to request more information contact Kat by email at kat.gialopsou@nottingham.ac.uk or at lpzkg@nottingham.ac.uk

FORTHCOMING AND RECENT TALKS ABOUT PARKINSON'S.

Make a note: 8th Annual INSIGHT into PD Online Conference, April 11th – 14th. Details to follow next month.

1. '*EVERYTHING YOU ALWAYS WANTED TO KNOW ABOUT MUCUNA… BUT WERE AFRAID TO ASK YOUR NEUROLOGIST'*. Monday, February 10th, 6.00-8.00pm

This talk and question session by Dr Rafael Gonzalez Maldonado is the next in the No Silver Bullet 4PD series. Dr Maldonado is a renowned neurologist in Granada and expert on Mucuna prureins. (MP). He combines clinical practice with teaching as an associate professor at the University of Granada. Currently, he works as a neurologist in a private Neurology practice in Granada, the Neuroconsulta Clinic. His clinic serves patients from all over the world thanks to online consultations. MP was the subject of a previous No Silver Bullet 4PD talk last October by Dr Roberto Cilia MD who is using it to treat Parkinson's patients in countries where levodopa is either not available or is not affordable.

The Editor adds: *MP is a legume found in the tropical and sub-tropical areas of the world. Many legumes (eg broad beans) contain some levodopa but MP is exceptional in that 6 – 9% of its weight is levodopa. So, it is no wonder that it is taken by some PwP as a complementary medicine to reduce their Parkinson's symptoms. In addition to Parkinson's MP has been investigated for its anti-diabetic, anti-microbial, antioxidant, anti-epileptic, and anti-depressant properties. Most PwP will be taking levodopa, but this is usually in combination with carbidopa which inhibits an enzyme in the blood which degrades levodopa so preserving levodopa's actions for longer. If you are thinking about taking MP you should discuss this with your Consultant and definitely read more about MP and its use in Parkinson's at:* ***this link.***

You could also check out the comments posted by PwP who have been trying MP. Some of these comments are on the Cure Parkinson's community pages of the HealthUnlocked website. This is a space for people with Parkinson's and those connected to them to share their experiences and opinions in an open and welcoming environment. Apparently, staff at The Cure Parkinson's Trust actively moderate the HealthUnlocked Cure Parkinson's Community so there is a connection from an oversight perspective. Comments from PwP using MP can be found at this link. If you get this February edition of the newsletter in time you can register for this talk through this link.

If you are too late to register, a link to the recording will be provided in the March newsletter. Or you should be able to find it by typing in '**nosilverbullet4PD**' and searching for the correct recording.

2. *'ADVANCING PARKINSON'S TRIALS DESIGNS'*. (This is the webinar described above).

This talk discusses how multi-arm, multistage (MAMS) clinical trial platforms are now being used to test multiple drugs at the same time. I discussed this in the December 2024 newsletter as it is an exciting and important way of speeding up the testing of several potential Parkinson's therapies at the same time. Some introductory reading to help us understand how MAMS platforms operate is given at this link.

Click **here** to access the webinar.

3. *'PARKINSON'S RESEARCH TAKEAWAYS FROM 2024 AND RESEARCH TO BE LOOKING OUT FOR IN 2025.'* Dr Simon Stott, January 13th.

If you feel that Parkinson's research isn't getting anywhere you should listen to this survey of Parkinson's drug trials which are in progress, which are due to report results this year and which may be starting up and require volunteers***. Yes, I know that such trials almost certainly won't help me (diagnosed 2014) but they do show that significant progress is being made.***

Dr Simon Stott is Head of Research at the Cure Parkinson's Trust and he also maintains the 'Science of Parkinson's' website at www.scienceofparkinsons.com which attempts to explain in plain English the research currently being conducted on Parkinson's. If you missed Simon's talk or want to hear it again you will find it here; https://youtu.be/QVvvjJcKz6A?feature=sharedy.

4. *'PREVENTING PARKINSON'S DISEASE'* by Dr Ray Dorsey.

This talk was given on December 16th last year so you should be able to find it on the No Silver Bullet 4PD website **at this link.**

Dr Ray Dorsey is a Professor of Neurology and director of the Center for Human Experimental Therapeutics at the University of Rochester, USA. He is working to identify and eliminate the root causes of Parkinson's. He is co-author of the book, "Ending Parkinson's Disease" in which he, Bas Bloem, Michael Okun and Todd Sherer lay out a plan to help prevent Parkinson's and improve care and treatment. Dr. Dorsey is investigating new treatments for movement disorders and is working on ways to improve the way care is delivered for individuals with Parkinson's and other neurological disorders. Using simple web-based video conferencing, he and his colleagues are seeking to provide care to individuals with Parkinson's.

5. The ASPro-PD study'

The PD Frontline research study team held a webinar online on December 12th, 2024, to hear updates about trials available to people who have taken part in the PD Frontline study. PD Frontline involves providing a saliva sample, which is then analysed to look for changes in genes which are associated with Parkinson's*.*

This talk described the upcoming ASPro-PD study, a trial of Ambroxol, the active ingredient of some cough medicines available in Europe but not the UK (though check out AmazonUK) In preliminary studies Ambroxol appears to slow Parkinson's progression. This trial will be recruiting in 2025 so if you are interested in participating it could be worth listening to the webinar. See this newsletter's section on Parkinson's research below.

To access a recording of the talk, copy this link into your browser: https://youtu.be/GEnR3insFuU.

6 MENTAL WELLBEING for PEOPLE WITH PARKINSON'S - A Team Approach, November 23rd, 2024 The Southeast Research Interest Group's Autumn Research Conference included the following speakers and talks: Emma Edwards, Parkinson's Specialist Nurse: 'Parkinson's and how to optimise our mental health' Dr Ian Cuthbert, Clinical Psychologist: 'Anxiety and Parkinson's - Causes and Effects' and Dr Emma Travers-Hill, Specialist in Brief Psychological Interventions, and Delyse Hammet, Counsellor: 'Counselling, Emotional Support and Self-Help Strategies'. If you want to hear these helpful talks or listen to them again click this link.

7. PAR-CON 2024

This excellent 2-day event held in October 2024 was organised by PwP's for PwP's. There were talks by experts on Revolutionary Research, Translational Technology, Hidden Symptoms, Living Well with Parkinson's, Managing Medication and Question sessions. There was a feeling of optimism at the meeting which comes across in the talks. If you missed the meeting or any of the talks you can catch them again by clicking this link which will take you to the whole PAR-CON content: https://www.youtube.com/watch?v=U6LcdaOvmx4&list=PL1ixQpbHed3bR815Vcx6KW_xVevii6j1d

PARKINSON'S RESEARCH NEWS

1. The Nottingham Universities' one day Neuroscience meeting 2025. This annual event brings together neuroscientists from the two Nottingham universities and wider afield. Not unexpectedly this years' talks covered a wide range of neuroscience topics but at least one by Dr Carlo Breda from de Montfort University, Leicester, was Parkinson's related. His work is about the block in the autophagy pathway that occurs in Parkinson's as discussed for GCase last month. Dr Breda is researching the role of a protein (RAB39B) which controls the movement of vesicles containing damaged cell constituents along the autophagy pathway to the lysosome for degradation. RAB39B is a molecular switch protein that once activated can turn itself off again: mutations in RAB39B can contribute to the development of Parkinson's disease by affecting the proper transport and recycling of cellular components, especially alpha-synuclein within neurones. ***Dr Breda will be describing his work in the March newsletter.***

2. The latest Cure Parkinson's Trust's (CPT) E-Newsletter is well worth a read. It backs up what you may have heard in Simon Stott's recent No Silver Bullet 4PD talk-see above and it should give some hope that big strides are being made in finding and testing treatments to slow or reverse Parkinson's progression.

There is a highly informative summary for each trial under the heading: '**2025: Cure Parkinson's research highlights from the last year and insights for the year ahead'**. Listed are Lixisenatide, DAPA-PD, low-dose lithium, Exenatide PD-3, the iLCT Pipeline Research Acceleration Grant Programme, CP-6, an iLCT screening study, the upcoming trial recruitment for ASPro-PD and EJS ACT-PD, AZA-PD, and the next quarterly webinar and the CPT's biannual Research Update Meetings. The extra descriptions of each of these drugs, trials, etc for further reading are very helpful.

You can access this CPT's E-Newsletter via *this link.*

More on Ambroxol

The Editor writes: Describing the new Ambroxol trial last month set me wondering how the researchers of the 2020 paper (***this link.***) worked out how much Ambroxol to give participants to keep within safe limits and to make sure the aims of the trial were achieved, eg can Ambroxol taken by mouth be detected in the cerebrospinal fluid showing that it can cross the blood-brain-barrier. The 2020 trial lasted for 186 days with doses over the first month building up to the highest concentration when for the remaining 158 days of the trial participants were taking 1.26g ambroxol/day (as 3 tablets of 420mg). In this 2020 study Ambroxol was donated by a pharmaceutical company.

The rationale for the 1.26g/day dose are explained in a methodology supplement to the 2020 paper and are based on a combination of human, primate and animal studies. In a 2016 study ambroxol was given to humans at daily doses of 1200 mg for 4 years, 1200 mg for 3 years, 1300 mg for 3 years, 625 mg for 0.5 years and 375 mg for 2 years measuring serum and CSF ambroxol levels over these periods. No significant adverse events were noted and Ambroxol was detectable at 0.06-0.83uM/L in CSF. To quote from the supplement 'We have reviewed animal, non-human primate and patient data and selected the 1260 mg/day dose to ensure efficacy in target engagement in the CNS, and detection in the CSF. The data indicate that a lower intake of Ambroxol may not penetrate the CNS or induce an effect necessary to enhance glucocerebrosidase activity'. It will be interesting to see if the same 1.26g/day intake of Ambroxol will be used in the forthcoming bigger Ambroxol trial.

Human nature being what it is some PwP have tried taking Ambroxol already. If you want to read their comments and see what dosing regimens they have followed their comments can be found on the Cure Parkinson's community website on HealthUnlocked. This is a space for people with Parkinson's and those connected to them to share their experiences and opinions in an open and welcoming environment. Here are two links to their comments but remember that these PwP are not on any official trial of Ambroxol with placebo controls so comments on effects are entirely subjective being based on personal feelings and opinions. file:///C:/Users/marti/OneDrive/Desktop/Feb%202025%20newsletter/(3)%20Anyone%20else%20taking%20ambroxol_%20Hello.%20My...%20-%20Cure%20Parkinson's.html and

file:///C:/Users/marti/OneDrive/Desktop/Feb%202025%20newsletter/(3)%20Ambroxol_%20What%20kind%20of%20results%20are%20people...%20-%20Cure%20Parkinson's.html

PARKINSON'S TRIALS NEEDING VOLUNTEERS TO TAKE PART PHYSICALLY AND/OR TO COMPLETE A QUESTIONNAIRE

1. '*Open Research for public contributors with lived experience'.*

'Open Research" refers to things that researchers can do to make research open and transparent. Currently there seems to be little opportunity for PPI contributors (also known as public contributors) to find out about 'Open Research'. **Ellen Poliakoff and her team** at the University of Manchester are looking for PPI contributors to take part in an online research study to find out about what you know, or would like to know, about 'Open Research. They are planning to use the survey results to create some new training materials about 'Open Research'.

What's involved? You will be asked to complete a short 15 – 30-minute online survey to share your thoughts on open research practices. The closing date is March 14th, 2025. You can find out more about the study in the attached participant information sheet – see below.

To take part you must have experience as a public contributor (You might refer to this as being a: lay member of the research team, co-production officer or a patient and public involvement volunteer), be over 18, be a fluent English speaker, and be able to complete an online survey on your own or with assistance. Ellen and her team may be able to help going through the survey on zoom or via the phone. You do not need to have any current knowledge about Open Research

To find out more information about the study, and to complete the survey please use this link. If you have any questions, or would like help completing the survey, please contact Ellen at ellen.poliakoff@manchester.ac.uk.

PS. ***You have the option of being entered into a prize draw for completing the survey.***

2. The Levodopa study

Consultant physician Dr Robert Skelly and Parkinson's Nurse Lisa Brown at Derby Royal Hospital seek information for their LEVODOPA STUDY on how you have coped if you have swallowing problems and have suddenly had to go into hospital.

Dr Skelly says 'Sometimes people with Parkinson's develop difficulties swallowing their food and/or their medication. If they have to be admitted to hospital in an emergency the doctors in the hospital may need to

change the usual Parkinson's treatment to something else such as a patch or treatment through a tube in the nose. We want to investigate what we believe is a better way to help people with Parkinson’s who have swallowing problem when they are admitted to hospital unexpectedly.
We will be applying to Parkinson’s UK for a grant to find a new solution to this swallowing problem. We will need your help in developing this project but first we need to collect background information to hear about your experiences. So, please contact us if:
A, You or a relative has been admitted to hospital and has not been able to take their usual Parkinson's medications due to swallowing problems or being too unwell, and
B,. Your Parkinson's medication was changed to a rotigotine patch or given through a tube in your nose’.

If both A and B apply, please contact us by email at dhft.pd@nhs.net or by phone on this dedicated number 01332 783535. Pleae state you are contacting us about the "Levodopa Study". Leave your name and phone number or email address. Either Dr Skelly or Lisa Brown will get back to you as soon as possible.

3. Get it on time: Parkinson's medication management while in hospital

The researchers aim to determine whether missed or delayed medication while PwP are staying in hospital can lead to health problems and unnecessarily extended hospital stays.

They need 350 people with Parkinson’s, who are taking Parkinson’s medication and who have recently had a hospital visit or have a visit planned in the near future.

What’s involved? You will be asked to complete one survey per month for 6 months following a hospital visit. The surveys can be completed online or by post and will take 30-40 minutes to complete. For more information, please read the **participant information sheet.**

If you are interested in taking part please register your interest by following **this link.** The deadline for taking part in this research is **1 June 2025**.

If you would like to take part by post or have any questions, please contact **Chesney Craig by email at c.craig@mmu.ac.uk or phone at 0161 247 5538.**

4. The TOP HAT trial of a licensed drug to treat hallucinations in Parkinson’s

The aim of the trial is to discover whether the already licensed drug **Ondansetron** has a meaningful treatment effect on the hallucinations some people experience in Parkinson’s. Ondansetron is an already licensed low-cost drug, and the organisers hope that if the research shows significant outcomes, Ondansetron could be available for people with Parkinson's who experience hallucinations within the next few years.

The trial needs 306 people diagnosed with Parkinson's or Dementia with Lewy bodies who:
a, experience visual hallucinations at least once a week,
b, are not taking apomorphine or any anti-psychotic medication, and
c, have been taking a stable dose of Parkinson's medication for 28 days before starting the research.

What is involved?
The first activity will involve a telephone call to discuss the research more fully, and to complete some questionnaires. This will be followed by a brief face-to-face visit to a local study centre (see below) to assess your Parkinson’s, take a blood sample, and monitor your heart rhythm.
If you are eligible to take part, you will either receive ondansetron or dummy medication tablets for 12 weeks, which will be shipped to you via a courier. The research team will maintain regular contact throughout to take assessments and let you know how much medication to take. This contact will be through telephone, video call, and face-to-face. 3 face-to-face visits are required, and for some research sites, home visits may be an option.

For more details, please read the Participant Information Sheet at **this link** or contact the TOP HAT team by email at o.zubko@ucl.ac.uk.
The nearest study centre in the East Midlands for anyone who wants to take part is at Sherwood Forest Hospitals NHS Foundation Trust, Kings Mill Hospital, Sutton In Ashfield, NG17 4JL **The deadline for taking part in this research is 1 July 2026.**

4. STEPS 2 - CAN ELECTRICAL STIMULATION IMPROVE WALKING?

Researchers from the Salisbury District Hospital and the University of Plymouth want to understand if a small electrical stimulation device can improve walking for people with Parkinson's.

Functional Electrical Stimulation (FES) is a technique that applies small electrical impulses through self-adhesive pads. These pads are placed on the skin over nerves that supply muscles that cause the foot to lift. Early testing suggests this may help to retrain movement.

The researchers need to recruit 234 people with Parkinson's who have difficulty walking due to Parkinson's, can walk 50 metres with walking aids, and can stand from sitting without assistance from another person.

What is involved?

If you are eligible to take part, you will either receive the study treatment, FES, for 18 weeks or your usual care for 22 weeks. You will be asked to attend visits to your local research site which are at Salisbury, Leeds, Swansea, Birmingham, Bangor or Cumbria.

Those receiving the study treatment, will attend 10 visits and those receiving usual care will attend 6 visits. The length of these visits will vary between 1 and 2 hours during which you will take part in tests to measure your movement, Parkinson's symptoms, and you will be asked to complete surveys. You will also be asked to complete a falls and exercise diary for the duration of the study. Travel expenses will be reimbursed.

Read the participant information sheet at **participant information sheet** for more information. Then contact the study team by email at **steps2.penctu@plymouth.ac.uk**.The deadline for taking part in this research is **31 August 2025** Unfortunately, those receiving Deep Brain Stimulation (DBS) or using other active medical implanted devices, such as a pacemaker, are unable to take part

5. IMPROVING QUALITY OF LIFE WITH AN ONLINE MENTAL HEALTH GROUP PROGRAMME

Becca Hunsdon, a PhD researcher at the University of Reading, has developed a new online group mental health programme to support the wellbeing and quality of life of people with Parkinson's (PwPs). The programme aims to provide tools to deal with unhelpful thoughts and feelings in a group setting. Beca now wants to test how effective the programme is for PwPs.

Becca needs: 50 PwPs who are experiencing anxiety or low mood who have a stable medication regime, with no changes anticipated in the next 12 weeks, who have not accessed psychotherapy such as CBT, counselling, or acceptance and commitment therapy in the past 12 months?

Unfortunately, those diagnosed with a mental health condition such as psychosis are unable to take part.

What's involved: Taking part in a 60-minute online introduction with the researcher, Joining 6 online group therapy sessions with between 3 and 7 other participants. These sessions will last between 60 and 90 minutes, completing homework tasks between each session and surveys which will take 25 minutes to complete.

All sessions will take place over Microsoft Teams and support is available for those unfamiliar with the software. You may be asked to wait up to 8 weeks before the programme starts.

For more information, please read the participation information sheet or contact Becca Hunsdon at **r.i.hunsdon@pgr.reading.ac.uk**.

To express an interest in taking part please go to *the researcher's website*, or contact Becca Hunsdon at r.i.hunsdon@pgr.reading.ac.uk. The researcher will then be in contact to discuss your participation. ***The deadline for taking part in this research is** 30 April 2025.*

6. CAN CBD (CANNABIDIOL) REDUCE SYMPTOMS OF HALLUCINATIONS AND DELUSIONS IN PEOPLE WITH PARKINSON'S

Around 3 in 4 people with Parkinson's will experience symptoms of hallucinations or delusions. Hallucinations can mean that the person sees, hears, or feels things that aren't there. This can be very distressing for the person and their loved ones. Current treatments for hallucinations and delusions are not very effective or come with unwanted side effects. That's why, in 2019, Parkinson's UK announced funding for CAN-PDP, an innovative clinical trial working with King's College, London, The trial aims to understand whether cannabidiol (CBD) may be useful for treating these hallucination and delusion symptoms in Parkinson's. CBD has been shown to have positive effects on other brain conditions such as epilepsy.

This trial needs 120 people with Parkinson's who are over 40 years old, who have experienced symptoms of hallucinations or delusions for at least one month, have been taking any Parkinson's medications for at least one month, are not taking clozapine and have someone who can attend visits with them to a local study centre

For the East Midlands *study centres are at the Royal Hallamshire Hospital in Sheffield, the Kingsway Hospital, Kingsway, in Derby or King's Mill Hospital, near Sutton-in-Ashfield.*

The deadline for taking part is March 1st, 2025.

For more information, read the *participant information sheet*.

For Sheffield contact Anna Emery or Alex Radford by email at anna.emery@nhs.net or Alex Radford alex.radford2@nhs.net).

For Derby the contact is Caroline Cheetham. Email: caroline.cheetham@nhs.net

For Sutton-in-Ashfield the contact is Sara Pisani, email: canpdp.trialoffice@kcl.ac.uk. Phone: 07936 545 178
If you have any questions, please contact the CAN-PDP Research Team by email at canpdp.trialoffice@kcl.ac.uk or call: 07936545178.

7. ANSWER A SURVEY ABOUT ADVANCED THERAPIES FOR PARKINSON'S

There are many health conditions, including Parkinson's, which lack treatments to slow or stop their progression. In the search for treatments, research is looking at potential non-drug treatments using methods such as cell, gene and tissue therapies. These are known as advanced therapies or ATMPs.

Dr Cheney Drew and Dr Kali Barawi have designed a survey to ask a broad range of people about ATMPs and ATMP research. They would like to understand how they can design research studies (including clinical trials) to include a more diverse range of people. This will help make sure that any new treatments that are developed are effective for everyone that needs them.

They need PwP, as well as partners, family members and carers to answer their survey online, at this link or by post by March 25th 2025. The survey should only take about 20 minutes to complete and they are particularly keen to hear from people from diverse backgrounds.

If you have any questions or would like to receive a paper copy of the survey, please email Kali at BarawiK1@cardiff.ac.uk .

PARKINSON'S UK RESEARCH SUPPORT NETWORK

This site advertises other trials needing volunteers. So click on the Take Part Hub on the Parkinson's UK website to find other research projects needing volunteers.

NEW GUIDE: EXERCISE, BRAIN HEALTH AND PARKINSON'S

Use the link below to access a downloadable new review of exercise and Parkinson's by the Michael J Fox Foundation. Nordic walking is included so see the Nordic walking talk at PEMRIG's September open meeting. Use **this link** to access the MJFF site.

Newsletter comments, queries, corrections, arguments, and submissions to the Editor (Martin Rumsby) at: martin69747@gmail.com. If you have any top tips for coping with your Parkinson's, special diets, exercise regimes, etc., that you would like to share with us in this Newsletter, email the editor. Any mistakes in the details above are entirely due to the Editor.